PA 13-242—SB 465
Public Health Committee
Appropriations Committee
Finance, Revenue and Bonding Committee

AN ACT CONCERNING NEWBORN SCREENING FOR ADRENOLEUKODYSTROPHY

SUMMARY: This act requires, once certain conditions are met, all health care institutions caring for newborn infants to test them for adrenoleukodystrophy (ALD), unless, as allowed by law, their parents object on religious grounds. Like existing law that requires these institutions to test infants for cystic fibrosis, severe combined immunodeficiency disease, and critical congenital heart disease, the test for ALD is in addition to the Department of Public Health's (DPH) newborn screening program for genetic and metabolic disorders.

Under the act, health care institutions must begin testing infants for ALD after both of the following occur:

1. (a) a reliable ALD screening method is developed and validated that uses dried blood spots and quality assurance testing methods or (b) the federal Food and Drug Administration approves an ALD test that uses dried blood spots and
2. any reagents necessary for the screening test are available.

EFFECTIVE DATE: October 1, 2013

BACKGROUND

Adrenoleukodystrophy (ALD)

ALD is a genetic disorder that causes the accumulation of very-long-chain fatty acids in the nervous system, adrenal gland, and testes, which causes a range of neurological, physical, and behavioral symptoms. While females are genetic carriers for the disease, it primarily affects males.

Generally, the disorder appears between ages four and eight, although milder forms can occur in adulthood. Childhood onset results in a long-term coma approximately two years after the development of neurological symptoms. The child can live in this coma for as long as 10 years.

OLR Tracking: ND:JKL:PF:ts